Colorado Cancer Coalition Priorities: 2016-2018

Option 2 of 10: **Cancer Prevention: Family History**
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Goal 3: Increased uptake of clinical interventions to prevent cancer.
Objective 3.1: Increase collection and use of family history to ensure appropriate and risk-based cancer prevention messaging, screening, and referrals.

➔ Strategies

- Support efforts, including those from the National Colorectal Cancer Roundtable, seeking to standardize family history data collection in electronic health records to allow providers to identify individuals whose family history meets the clinical criteria for a hereditary cancer syndrome and those who should be referred to a genetic counselor.
- Educate providers on guidelines for family history collection and referral for genetic counseling and testing, including potential BRCA1/2 mutations or Lynch Syndrome.
- Conduct demonstration projects that implement family history screening tools in primary or specialty care settings to identify patients at risk for hereditary cancer.
- Develop referral and communication systems to facilitate on-site or referred cancer risk assessment, genetic counseling, including tele-counseling, and testing services by a qualified genetics professional.
- Promote access to genetic counseling based on risk assessment prior to genetic testing to review potential risks and benefits, including post-test risk and benefits when prophylactic options are under consideration.
- Identify funding sources for genetic counseling and testing for at-risk individuals who are unable to pay.
- Promote appropriate insurance coverage, especially Medicaid coverage, of genetic counseling, testing and ensuing clinical services for high-risk individuals.

➔ Measures

	Data Source	Baseline	2020 Target
Adults who discussed their family's history of cancer with a health care provider.	2016 BRFSS	TBD*	TBD
Adults with a close family member diagnosed with breast or colorectal cancer who are up to date with modified cancer screening recommendations.	2016 BRFSS	TBD*	TBD

**The 2016 BRFSS questionnaire includes two new questions on cancer family history. The baseline measure and target will be identified once the 2016 BRFSS data is released, likely summer 2017.*

➔ What we know about the problem

- **Hereditary cancer is rare, but important to identify**
  - Estimated 5-10% of cancers are due to mutations in single genes that cause cancer to "run in a family" (known as hereditary cancer).
  - Individuals with hereditary cancer predisposition are much more likely to develop cancer than the general population, are more likely to develop ANOTHER cancer if they survive the first, and tend to be diagnosed at younger than usual ages (e.g. breast cancer risk in BRCA1 gene mutation carriers can be as high as 87%, compared to the 10-12% risk for most women; and their risk for ovarian cancer is up to 44% vs. <1%).
  - An individual with hereditary cancer predisposition has a 50% chance to pass it down to each of their children, regardless of gender. It was often inherited from a parent and may be present

in siblings and extended relatives. Therefore, the diagnosis of hereditary cancer can give important information for family members.
    - Medical management options are available for people with hereditary cancer that are different from the general population. These options can help prevent cancer, or detect it earlier when it may be easier to treat. Information about hereditary cancer status can be life-saving. For example, surgical removal of the ovaries can reduce ovarian cancer risk by 96%, and breast cancer risk by as much as 68%.
    - Even if hereditary cancer is not diagnosed, family history can impact screening recommendations.
- **Hereditary cancer is under-diagnosed**
    - Based on the estimated prevalence of mutations in the population, and testing data from a major commercial laboratory, it is estimated that >1.1 million people in the US with a BRCA1/2 mutation or Lynch syndrome are still undiagnosed.
        - Despite NCCN guidelines recommending all women with ovarian cancer be offered BRCA1/2 testing since 2008, only 27% of ovarian cancer patients had been tested as of 2013 [Herzog et al. Poster presented at SGO 2015]
        - CO was only slightly higher than the national average, at 30.5% Studies have shown that most women with ovarian cancer want to know their BRCA1/2 status [Lacour et al. et al. *Gyn Onc* 2009]
    - Healthcare providers need these 3 steps to diagnose hereditary cancer:
        - Collection and evaluation of personal and family history of cancer
        - Recognition of the warning signs of hereditary cancer, and indications for testing
        - Provide enough information to the patient about hereditary cancer for informed consent/denial of genetics services (testing or genetic counseling referral)
    - A recent study looked at 10,000 medical records from 212 oncology offices, 71% of medical charts were missing a complete cancer family history; most often missing ages of diagnosis in family members [Wood et al. *JCO* 32.8 (2014)].
        - Incomplete cancer family history will miss a significant number of patients at risk for hereditary cancer [Solomon et al. *JCO* 32.5 (2014)]
            - 62% are missed if information on only first-degree relatives is assessed (parent, sibling child)
            - 32% are missed if information on only first- and second-degree relatives is assessed (second-degree includes aunts, uncles, grandparents, nieces, and nephews)
            - The National Comprehensive Cancer Network recommends assessment of first- second- and third-degree relatives (third-degree relatives include great grandparents, great aunts/uncles, cousins, grandchildren, and great nieces/nephews)
        - Because family history and testing guidelines change over time, the family history must be periodically updated and re-evaluated.
    - Even if patients are identified as being at risk for hereditary cancer, referral drop-off rates to genetic counseling range from 33-73% [Cohen et al *J Genet Counsel* 2009, Lauritzen et al *J Genet Counsel* 2014].

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➔ **Why should CCC members prioritize this area of work?**

Prioritization factors	Considerations	Notes
Likelihood of Population Impact	Estimated % of population at risk for hereditary cancer: ➔ General population: 2-5.9% ➔ Breast: 37% // Screening mammography: 6.2% ➔ Colorectal: 25% // Endoscopy clinics: 20% ➔ Ovarian: 100% ➔ Endometrial: 30%	
Evidence of Feasibility	• Multiple online family history questionnaires are available that collect family history and automatically evaluate for hereditary cancer red flags. The shortest online family history questionnaire takes ~30 seconds to complete. • Paper family history forms are also available that have red-flags contained within. • Colorado has 23 cancer genetic counselors, located in Denver metro, Colorado Springs and Grand Junction. Telephone counseling, by Informed DNA, is available nationally.	
Established Need	• Nationally, 1.1 million undiagnosed high risk patients. • Data not available for CO, but ovarian gap is consistent with national numbers.	
Measurability	• Data is forthcoming based on 3 BRFSS family history questions being asked in 2016, but the results won't be available until mid 2017. • Data could also be gathered from imaging centers and oncology providers to estimate the "gap"	
Collective Impact	• An independent party, like the CCC, can help bring individuals and organizations together to make a recommendation and impact this work.	
Identified Gaps	• Awareness and buy-in is needed by healthcare providers in order to learn and implement a new screening/assessment tool. • Reputable community organizations may have a major impact.	
Opportunities for Leveraging partnerships	• The Colorado Cancer Genetic Counseling Community is strong. • Partnering with hereditary cancer testing companies to actively promote family history collection and evaluation in Colorado could also prove successful.	
Political/ community support	• At the federal level, the US Surgeon General and CDC have family history awareness tools. • In Colorado, the breast, ovarian and colorectal communities are engaged and interested in moving this work forward.	

Would you or your organization commit to helping with this priority?